

Chapter 5

**ASSESSING THE END-OF-LIFE-CARE
EDUCATIONAL NEEDS OF ELDERLY DEAF PERSONS:
LESSONS ON LANGUAGE AND CULTURE
FOR RESEARCHERS AND HEALTH PRACTITIONERS**

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ABSTRACT

This chapter reports on a community-based participatory research (CBPR) strategy for collecting health related data from a linguistic minority in the United States: self-identified members of Deaf community. The literature available on deaf and hard of hearing persons' health and healthcare status suggests that these individuals rarely participate in surveys of citizens' well-being. Recent work assessing "health literacy" among hearing adults, shows that obstacles to gaining healthcare information, including limited proficiency in English, impede healthcare knowledge, utilization, and costs, as well as health itself. Culturally identified Deaf individuals often view researchers from the "hearing world" with suspicion. Using CBPR and ASL-GLOSS (an American Sign Language—ASL—linguistics method) trained Deaf interviewers asked 130 Deaf senior citizens who depend on a signed language for communication about cultural practices and linguistic barriers to healthcare, focusing on end-of-life care information.¹ Interviews were videotaped, while a centrally located monitor received direct feeds from five enclosed interview booths allowed the research team to make adjustments to ensure consistency among interviewers during the study. A mirror placed behind the respondents enabled interviewer and respondent to be captured on the same videotape. The closed-ended questions of the half-hour interviews were coded on-site by the Deaf interviewers for statistical analysis. A team of Deaf interviewers reviewed the tapes to check the reliability of the initial coding and assign categories and codes to open-ended questions. A focus group comprised of expert Deaf interviewers, community leaders, and hearing

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researchers reviewed and interpreted the findings. The survey instrument and method revealed important findings concerning deaf senior citizens' perceptions about their end-of-life care needs, enabling the development of appropriate educational materials and information dissemination strategies. The research team concluded that the conceptual, sociocultural, and linguistic challenges of culturally identified deaf and hard of hearing persons can be addressed using CBPR strategies and ASL-GLOSS linguistic methods. These innovations in survey design and method can have a significant impact on collecting valid and reliable data from this underrepresented population. Moreover, the research experience speaks to the broader concern of health literacy among members of the Deaf community.

INTRODUCTION: THE LESSONS INSPIRING COMMUNITY-BASED PARTICIPATORY RESEARCH

In 1999, eight Deaf and two hearing Minnesotans established the leadership team of *The End-of-Life Care Education Project of the Minnesota Deaf Community* (the Project).¹ The team's aims included training Deaf hospice volunteers and producing linguistic and culturally appropriate end-of-life care educational materials for Deaf people and their families. The tremendous response of healthcare professionals and Deaf families to the Project's activities underscored not only this population's need for access to information and services, but also the educational needs of professionals charged with providing services for this community. Several experiences in hospice care settings revealed barriers to communication: Project-trained volunteers encountered Carl, whose brain injury made his signing legible to only those whose first language was American Sign Language (ASL); the volunteers also met Clara, a ninety-year-old woman who was the only Deaf resident at her care facility, cutting her off from all social intercourse. In Carl's case, communication barriers brought humiliation until Deaf volunteers explained to caregivers that his small gestures were in fact the ASL sign for "toilet" (Allen et al. 2002). In Clara's case, Deaf volunteers were able to show that Clara's lack of communication was not a manifestation of dementia, but an artifact of the linguistic isolation of a lucid elderly adult, with limited English literacy skills and a cultural reluctance to confide in a hearing person (a hospice chaplain).

Anecdotal reports suggested other significant obstacles to healthcare and information, including, for example, caregivers who relied on a Deaf patient's hearing family members for interpreting, not realizing that their patient might withhold important information about symptoms, rather than risk embarrassment (see also Committee on Disabilities of the Group for the Advancement of Psychiatry 1997) or a family member who may be reluctant to pass on difficult news. Differences within the deaf population—age of on-set of deafness, residential school experience versus mainstreaming and a variety of communication preferences—further indicated the complexity of addressing the informational and care needs of the Deaf community. As Project team members considered the formal assessment of Deaf senior citizens' needs for health and end-of-life care information, it seemed clear that to

¹ We use the lowercase *deaf* when referring to the audiological condition of not hearing, and the uppercase *Deaf* when referring to a particular group of Deaf people residing in the United States and Canada who share a culture,

generate reliable, valid, and useful knowledge, members of the community could benefit greatly by collaborating with and using the expertise of academics, in this case social scientists. Members of the Deaf community initiated the collaboration, making it all the more critical that Deaf people be involved in all aspects of the study—from constructing linguistically and culturally appropriate questions to interpreting results.

COMMUNITY-BASED PARTICIPATORY RESEARCH

Community-based participatory research (CBPR) begins by acknowledging the community as an aspect of collective and individual identity (Israel 2000; Israel, Parker, and Becker 1998). Indeed, in response to our question in Figure 1, our study found that a majority of Deaf seniors (65%) see themselves as “Deaf” first and as members of the United States polity second.

The next question is about how you identify yourself, or what you call yourself.
**WHICH YOU WANT IDENTIFY YOURSELF? WHICH
 FIRST DEAF, SECOND AMERICAN.
 FIRST AMERICAN, SECOND DEAF, WHICH?**

	N	% Responding
1. Deaf American	80	65.0
2. American who is deaf	36	30
3. “R” sees no difference	6	5
Total	125	100.0

Figure 1: Primary Identity

Other principles of CBPR include: building on the organizational strengths, relationships, social structure and other resources of the community/culture; collaborating as partners in all phases of research (iterative processes of design, data collection and analysis); and creating opportunities for co-learning and empowerment in the interpretation and dissemination of results.

Community-based research (CBR) has revealed important cultural differences related to healthcare, a first step in increasing the relevance of research, identifying intervention strategies and adopting “best practices” within studied communities. By adding *participation* to the CBR philosophy, researchers in diverse communities have not only furthered these aims, but also enhanced trust and mutual respect among community members, researchers, and health professionals. CBPR has been shown to empower community members, enabling them to redirect their resources toward educational and action programs designed to promote well-being in their community. (CDC 1997; Hall 1992; Schulz, et al. 1998.).

In sum, CBPR partnerships join participants with diverse skills, knowledge, and expertise to address complex problems (Butterfoss, Goodman, and Wandersman 1987; Hall 1992; Himmelman 1992). Our experience suggests that CBPR played a vital role in collecting and

use sign language as their primary means of communication among themselves, and hold a set of beliefs about

interpreting data as well as in disseminating educational materials based on study findings. The sustained commitment of the researchers and Deaf community members in implementing “best practices” has produced subsidiary partnerships among Project team members, local institutions of higher education, Deaf (and hearing) hospice volunteers and practitioners, healthcare providers, and Deaf individuals and their families (see also Israel, Schurman, and Hugentobler 1992).

HEALTHCARE RESEARCH AND THE DEAF COMMUNITY

Nearly 23 million people (9.35% of the population) in the United States are categorized as having a hearing loss; approximately 4.8 million of these individuals cannot hear or understand speech (Adams, Hendershot and Marano 1999, Table 62, p. 93; Barnett 1999; Harmer 1999, Tamaskar et al. 2000). For those who are pre-lingually deaf and many others for whom deafness resulted from disease or injury at an early age, signed language is the primary mode of communication. Following Spanish, American Sign Language (ASL) is the second most commonly used minority (non-English) language in the United States (Barnett 1999); researchers estimate that at least two million Americans use ASL for everyday communication (Zieziula 1998). Although ASL represents the first language of a sizable number of Americans, there is no national database on deaf and hard of hearing (D/HOH) persons and little reliable data on the demographics, morbidity, or mortality of the deaf population or the ASL language group. For example, a recent examination of data sources of potential value for assessing the health and healthcare status of D/HOH on Medicare raised serious doubts about the reliability of the Medicare Current Beneficiary Survey (MCBS); 20% of people reporting a hearing loss in 1998 report normal hearing in 1999 and only 47% of people identified as deaf on the MCBS in 1998 also indicated that they remained deaf a year later (Delmarva Foundation and Gallaudet Research Institute 2002). The National Health Interview Survey (NHIS) records numbers of “hearing impaired” persons (Adams, Hendershot, and Marano 1999), but the survey does not distinguish the members of the distinct linguistic group—users of signed language—who were the focus of the present study.

The Deaf community is a unique languaculture (Agar 1994) whose members share a common language and history and participate in the formal societal structure of this distinct group (Becker 1980; Cohen 1995; Lane 1996; Lane 1993; Padden and Humphries 1988; Parasnis 1996; Sacks 1994). Research on this population’s health and healthcare status remains extremely limited (Barnett 2002) and findings on medical care resource-use patterns are inconsistent (Delmarva Foundation and Gallaudet Research Institute 2002). Two results are remarkably uniform across all studies: 1) language differences raise a significant obstacle to the adequate care of Deaf individuals and 2) this population must be aggressively sought out and included in the national research agenda to improve the quality of healthcare for culturally diverse populations.

Differences in language and culture between the majority hearing population and Deaf people influence the healthcare provider-patient/client relationship (Barnett 2002b; Barnett 1999; Dipietro 1981; Ebert and Heckerling 1995; Harmer 1999; Lotke 1995; MacKinney et al. 1995; Shelp 1997; Solow 1981); may impede diagnostic and other aspects of healthcare

themselves and their connection to the larger society (Padden and Humphreys 1988).

provision for this linguistic minority (Harmer 2002; Iverson 2000; MacKinney et al. 1995; Steinberg, Sullivan, and Loew 1998; Zazove et al. 1993); and may significantly limit the Deaf individual's information on prevention and treatment of serious medical conditions (Baker-Duncan et al. 1997; Ebert and Heckerling 1995; Harmer 1999; Joseph 1995; Lass et al. 1978; Tamaskar et al. 2000; Woodroffe et al. 1998; Zazove 1997; Zazove and Doukas 1994; Zazove et al. 1993). In the context of end-of-life care, language and cultural differences have an impact on the quality of end-of-life care and decision-making as well as bereavement counseling for dying persons who are Deaf, their family members, or Deaf persons who grieve the loss of family members, whether they are hearing or Deaf (Hines 2002; Zieziula 1998). The growing understanding of health literacy also presents additional concerns for all cultural and linguistic minority populations – including members of the Deaf community. (Nielson-Bohlman, Panzer and Kindig 2004.) The combined forces of a vastly different language, the relative isolation of the community with undefined geographic boundaries, as well as cultural differences and limited health literacy present significant challenges in creating a data base of reliable, valid research. (Barnett 1999; Li et al. 2001).

Telephone surveys, while relatively inexpensive, under-represent this population (Barnett and Franks 1999) and, for reasons discussed at greater length below, self-administered (written) English questionnaires most likely will be unreliable. Yet, the costs of interpreted interviews, translation and transcription to written English for the purpose of data analysis can be significant. Sampling also presents a research challenge, given the difficulties in identifying the portion of the population classified as D/HOH and the lack of registries for users of ASL, one indicator of affinity for the Deaf community. In many populations, the use of fortuitous samples (e.g. drawn from the membership of social organizations or responding to study advertisements) is generally acknowledged to introduce the potential for bias. Deaf clubs in towns and cities as well as national organizations draw from a highly networked population bound by residential school ties, highly subscribed local and national Deaf media, and annual national social and sports event gatherings (Becker 1980; Lane 1996; Lucas, Bayley, and Valli 2001; Padden and Humphries 1988; Parasnis 1996; Sacks 1994). Researcher biases—which can occur in instrument design, data collection and the interpretation of findings—may present an even more significant challenge than sampling bias for those who attempt to study this relatively closed community. A history of mistrust of hearing health professionals and academics compound the difficulties of research within this non-English language community (Barnett 2002b; Lane 1993; Li et al. 2001; Padden and Humphries 1988).

Beyond our experiences which led to the adoption of CBPR as a general research strategy, the reports of other researchers indicate three additional lessons for studies of Deaf individuals: 1) An interview protocol administered in person by a trained interviewer is preferable to a self-administered written survey or telephone interview; 2) Interviews should be conducted in the first language of the respondent (most often a signed language); 3) The benefits of fortuitous samples may mitigate the potential problems of bias. Further review of the literature on signed languages and Deaf culture suggests other factors affecting the researcher's ability to collect reliable data about Deaf people who use ASL as their primary mode of communication.

SIGNED LANGUAGE AND DEAF CULTURE

In addition to the many anticipated challenges posed by language differences in cross-cultural studies, the linguistics of ASL raises several unique issues for researchers (Allen et al. 2002; Barnett 2002a; Barnett 2002b; Zazove 1997). ASL is a visual language whose signs are not adequately represented in written form (Baker-Shenk and Cokely 1991; Valli and Lucas 2002). The structure and grammatical characteristics of ASL are independent of English (Liddell 1980); *American Sign Language* designates the name of a language used by Deaf persons in North America, not (as is commonly believed) the signed equivalent of English. ASL provides no immediate or general access to the English language or any other spoken language.

The acquisition of English or another spoken language is extremely difficult for people who cannot hear (Hansen 2002). For most pre-lingually (and, depending on the individual's age of onset of hearing loss, many post-lingually) Deaf persons, English remains a second language (Caprici et al 2002; Liddell 1980; Lotke 1995; Moores 1997); average English reading levels for Deaf Americans have hovered around the fourth-grade equivalent for several decades (Holt, Traxler, and Allen 1997; Livingston 1997). As a result, the use of written English language questionnaires and other written modes of English-based communication between Deaf and hearing individuals are potentially unreliable. Questions phrased at the fourth-grade reading level may fail to reflect adequately the cognitive sophistication and depth of experience of Deaf respondents and question translation may be inconsistent across ASL interpreters. More significantly, important differences in the language, including the lack of homonyms, non-equivalence of metaphor, simile, and idiom, and the representation of some parts of speech (e.g. pronouns) by spatial references rather than signs, may give ambiguous meaning to *validated* English-language measures (Baker-Shenk and Cokely 1991). For example, anecdotal evidence reveals the depth of such problems in the contemporary example of the misinterpretation of the multiple meanings of the English term "positive," which leads Deaf individuals to understand their HIV+ status as a beneficent sign of health (See also Barnett 2002a).

Inconsistent interpretation of English constructs only increases the potential for data collected in English to be invalid or unreliable. Written questionnaires or ASL interpreted English-questionnaires that have been pre-tested on a Deaf sample may be adequate for the cost-effective measurement of some constructs (e.g. self-reported health habits such as smoking and alcohol use, number of visits to the doctor annually, and demographic data) (Lass et al. 1978; Tamaskar et al. 2000; Zazove et al. 1993), but a more complete picture of Deaf persons' experiences, beliefs, attitudes, and behaviors related to healthcare and end-of-life care may well necessitate multi-method approaches consisting of qualitative indicators and quantitative measures utilizing ASL (MacKinney et al. 1995; Witte and Kuzel 2000) and, for some constructs, Deaf interviewers and focus-group facilitators (Allen et al 2002).

The unique language, values, and history of Deaf culture imply not only that construct validity, but also the accurate interpretation and acceptance of findings may depend on the continuing participation of members of the Deaf community in all research agendas. Unlike other minority languacultures, the Deaf community is often pathologically defined, an issue that continues to provoke distrust of medical professionals among individuals who define themselves as members of a distinct cultural minority (Lane 1993; Padden and Humphries

1988). In contrast to individuals who become deaf or hard-of-hearing later in life, many pre-lingual deaf individuals do not express their Deaf identity as a deficiency or the condition of deafness as a loss or lack. Rather, they present Deaf identity as one of the myriad distinct possibilities for the human being and, indeed, no data suggest that the lives of Deaf persons are less fulfilling than those of other (hearing) communities (Barnett 2002a; Barnett 2002b; Committee on Disabilities of the Group for the Advancement of Psychiatry 1997; Sacks 1994; Zazove 1997). Our study confirmed these findings and provided additional information about the residential school experience, socialization, and barriers that continue to impede access to adequate health information.

Most Deaf seniors in our sample created lifelong bonds with their residential school cohorts maintaining friendships that transcend geographic separation. In contrast, they shared a common language with neither their hearing parents nor, in most cases, their hearing siblings (Allen et al. 2002; Lane 1993; Padden and Humphries 1988). Ninety-five percent (a statistic that has remained remarkably consistent) of all deaf children are born to hearing parents showing similar results for our sample) many of whom do not learn ASL. Our sample population responded similarly (see Figure 2). For similar reasons, Deaf culture, thus, differs in how it is transferred among its members. Unlike other cultures, the language, norms and values of Deaf culture are transferred from peer to peer (“horizontally”) instead of intergenerationally (“vertically”) from parent to child (Barnett 2002a; Becker 1980; Committee on Disabilities of the Group for the Advancement of Psychiatry 1997; Parasnis 1996; Sacks 1994). Whether it is Deaf children with hearing parents or Deaf parents with hearing children, horizontal transference of culture presents significant issues for end-of-life caregivers and practitioners, including who is defined as “family.”

Did you attend a residential school for Deaf children?	
FINISH WENT DEAF INSTITUTION?	
Were Your Parents Hearing?	
YOUR PARENTS HEARING?	

		N	% Responding
4. Attended Residential School	Yes	113	91.1
	No	11	8.9
	Total	124	100.0
5. Both parents hearing	Yes	117	94.4
	No	7	5.6
	Total	124	100.0

Figure 2: Residential School Attendance and Parents' Hearing Status

As Figure 2 shows, a preponderance of our sample population lived in residential schools, some up to 14 years. Most students returned home to their family of origin only at holidays severely limiting opportunities to participate in many family rites and rituals, including those related to death. Indeed, these respondents' views of “family” inclined to friends who shared the formative experience of Deaf residential school culture, rather than the biological tie generally understood by the majority culture as the basis of kinship (Allen et al.

2002; Becker 1980). The residential school experience influenced not only patterns of socialization, but also changed the individual's understanding and orientation to healthcare practices and information. Separation from the family of origin limited this population's access and understanding of such basic information as family medical history—indeed, anecdotal evidence indicates that in many cases, linguistic barriers prevented these Deaf seniors from knowing their own medical history (Allen et al. 2002; Barnett 1999; Clark 1995). As other studies have shown, children may not learn the causes of their illnesses when they do not share the language of their adult caregivers. Examination of residential health education curricula and preventive care instructions given by parents (or teachers) who do not use ASL also suggests that information may be limited to behavioral commands, without reference to the rationale for a given action (e.g. “brush your teeth,” omitting the reason, “so you don't get cavities”) (Clark 1995).

In addition to the language and cultural differences that distinguish this languagculture from other diverse populations is the lack of exposure to “incidental information”—news passively received by overhearing conversations, radio or television in the course of mundane activity. Lack of access to this kind of information, which plays a significant role in a person's ability to gather and analyze new concepts and ideas, generally is not accessible to Deaf persons, placing them at an even greater disadvantage when compared with their hearing counterparts. These factors—the lack of a common language and, in most cases, the cumulative experiences shared across generations with the family of origin as well as the inaccessibility of incidental information—have a profound affect on a Deaf persons' store of background knowledge. The existence of a sign for “background knowledge” illustrates the degree to which this reality is recognized within the broader Deaf community. The understanding of this concept (confirmed by the existence of a sign) stands in stark contrast to the lack of a sign for “hospice” or “advanced directive”—concepts not understood prior to the development of workshop materials and videotapes resulting from our research. The lack of background knowledge and access to information created a system of peer learning to fill information gaps, generating extensive networks that may amplify as well as correct misinformation (Becker 1980). Our findings suggested two related results: 1) gaps in background knowledge must be addressed before concepts relevant to end-of-life care can be made wholly intelligible and 2) the Deaf communication network is a highly evolved, sophisticated medium into which new information may be introduced (Allen et al. 2002).

Finally, the visual quality of ASL makes face-to-face communication essential, further encouraging the extensive relational networks at the core of the culture. Not only practical information, but also the literature and history of this culture are conveyed primarily in settings that allow for face-to-face interactions. Technological changes, including telecommunication devices (TTY/TTD) and e-mail, have enhanced rather than supplanted the cultural value of these networks. For all of these reasons, the norms of this “relational culture” must play an important role in the design of end-of-life care research. We believe that by addressing the unique characteristics of this population through a CBPR strategy, we have developed prototype research instruments that will allow other researchers to discover reliable and valid knowledge about the Deaf community in the healthcare setting.

Hearing individuals may not immediately grasp the profound difference between acquiring a spoken language by hearing the language, and relying wholly on learning a language in its written form. ASL is acquired naturally; concrete experiences and abstract concepts are transmitted with the immediacy of a spoken language (Capirci et al. 2000;

Lucas, Bayley, and Valli, 2001; and Washabaugh, Woodward, and DeSantis 1980). Nevertheless, the task of composing a grammatically correct English sentence without the benefit of modeling by hearing conventional usage requires additional skills that must be painstakingly acquired (Gallaudet Research Institute 1996; Gray 1956; Hansen 2002; and Holt, Traxler, and Allen 1997). Depending solely on English for communication with Deaf individuals invariably increases the probability of misunderstanding and stress.² Deaf elderly patients are not cognitively impaired, nor do they have limited life experience or suffer from an inability to communicate all the subtleties of emotion and ideas about their experience – in their own language. They will however, like most of us have difficulty communicating the full range of experiences very well in a second language. In that the Deaf individual may need to attain English proficiency to function in the hearing world, that hearing world has an ethical obligation to address barriers to communication in the healthcare setting.

Implications of Signed Language for Health Research and Care

A brief summary of some of the key elements of the language will illustrate the depth of the issues Deaf people, researchers and healthcare professionals may encounter when communicating with one another. ASL, in summary, is a nonlinear language using space, facial expressions and hand and body movements, fully exploiting the capacities of vision, spatial relations, and visual-kinetic memory for storing and processing concurrent layers of information (Lane, Hoffmeister, and Bahn. 1996, 91). Facial expressions, “non-manuals,” convey meaning. They include adverbs and information about sentence structure and organization. Linguists have identified over 250 grammatically governed facial expressions in ASL. Yet, while these signifiers may be described, they involve subtle movements of face, tongue, eyes, eyebrows, lips, and mouth, and cannot be represented as written symbols.

ASL also displays grammatical elements such as the actors and objects of actions spatially. By pointing to a space(s) in front of the signer’s body, the signer is able to use spatial arrangements to carry complex meanings that would require a lengthy text or explanation, if the same information were to be conveyed in a spoken or written language. The location of the sign relative to the body also carries information and can change the meaning of the sentence—including signs for “past,” “present” and “future.” An individual communicating her/his “pain” would perform that sign in the location where the pain occurs. Locating the sign by the temple for example, would indicate the individual has a headache.

Whether it is for purposes of conducting survey research or assessing pain, a very basic understanding of the linguistics of ASL can be instructive and increase one’s appreciation for why some research with this population has produced unreliable data. A brief example illustrates the linguistic rule that signifies and distinguishes interrogative from declarative statements. “Yes/No” questions must be marked by raised eyebrows; “Wh-questions” (what, where, when, why and how) must be indicated with eyebrows down. To ask the question, “do you have any pain?” with eyebrows down is not only grammatically incorrect it may make some communication confusing. A recent study of the neurological controls of facial

² The Project conducted three focus groups in which participants viewed three closed-caption videotapes about end-of-life care. Participants unanimously agreed that the English language usage was an obstacle to their learning about healthcare information.

expressions of Deaf signers confirms two distinct functions of facial expressions — affective and linguistic. (Corina, Bellugi, Reilly, 1999.) Now consider the “Faces Pain Rating Scale,” (Figure 3) a visual scale that often is used to help healthcare providers assess a patient’s level and type of pain (Herr 2002; Herr 1998; Herr and Garland 2001; Herr, Mobily, Richardson, and Spratt 1997; and Wong and Baker 1988). The intent of the Faces Pain Rating is affective and in ASL has no linguistic association with pain (Herr 1998).³ Rather, the linguistic function of the facials illustrated in Figure 3 are co-occurring facials used with the signs for happy, glad, surprise, depressed, sad, and cry (Costello 1994).⁴

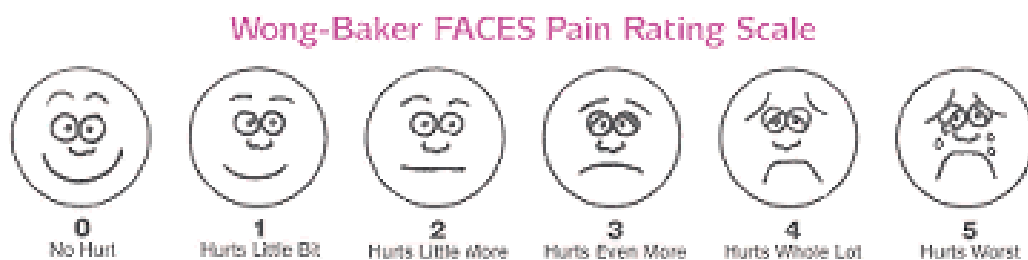


Figure 3.

Numeric Pain Rating Scales (NRS), another popular pain assessment tool, rank orders pain numerically along a horizontal continuum that is typically graded as an interval measure ranging from zero to five, arrayed from left to right according to English language reading conventions. This spatial orientation has no meaning in ASL, where such ordering bears no connection to gradations of measurement, but often carries other meanings that convey depth and detail in the essentially non-linear narrative form of the language. We will address similar difficulties with Likert scales later in this chapter.

Mindful of the centrality of facials to ASL, we asked a few Deaf adults to tell us their opinion about probable results in using the Faces Pain Rating Scale (FPRS) with members of the ASL linguistic community. The results of this informal survey suggested that Deaf people, particularly individuals who are more vulnerable or with low reading literacy, might find the facials confusing. When symbolic faces are used in print to convey sentiments, they carry another set of meanings. Since humor, and teasing cannot be communicated and understood by voice, Deaf people often use words [(smile) or (haha)] parenthetically in the body of their TTY or e-mail messages and have adopted a series of keystroke conventions to convey specific affects. In fact, in one edition of a widely circulated national Deaf newspaper, *Silent News*, the entire back page was devoted to the keystrokes used to make a variety of

³ Comparisons of various scales including the faces pain scale (FPS) (horizontal) numeric rating scale (NRS) given below, vertical visual analog scale (VAS), verbal numeric scale (VNS) and verbal descriptor scale (VDS) show that the age does not significantly effect the use of the FPS. Higher levels of pain were reported using the VNS and the VDS discriminated best between increasing intensities of pain. The VAS was subject to higher failure rate, as was the NRS when administered repeatedly in short periods of time.

⁴ These scales are among the pain assessment tools made available to palliative care providers on many websites, including *Partners Against Pain* as cited, <http://www.partnersagainstpain.com>, accessed 5/10/02 and the American Medical Directors Association, <http://www.amda.com/clinical/chronicpain/pain-face.html>, accessed 5/15/02. Although neither organization recommends the use of this scale in groups other than those intended by Wong and Baker (1988), it has increasingly been accepted for use with adults under palliative care.

“smiley faces.” This range of “faces” seems to have found a place within the culture unrelated to any associations with the somatic conditions of pain.

Difficulties in communication pose similar difficulties in collecting data and disseminating information within the Deaf community. Our goal of obtaining a representative national sample required that the vast majority of the Deaf seniors be able to comprehend and answer our questions accurately. The only way to achieve this goal was to administer surveys in ASL—in *their own language*—thereby allowing our Deaf respondents to communicate the subtleties of emotion and ideas about their experience. Beyond the question of language proficiency lie other issues, including cultural differences, which language holds in the deep recesses of interpretation and meaning.

Cross-cultural study may intensify problems typically encountered in social science research, including well-known tendencies toward response bias and similar concerns. Social scientists find that respondents often try to accommodate the researcher, giving what the respondent perceives as the popular, appropriate, or desired answer to a question. In cross-cultural research this particular bias is increased, especially if respondents are of a minority culture or language group—or simply perceive themselves to differ from the enculturated assumptions displayed by the researcher, research instrument, or research methodology. Using the first language of the respondent is a necessary to gather accurate information about respondents’ preferences, attitudes, and behaviors in cross-cultural research, but linguistic translation is only the first step toward effective cross-cultural communication.

Health Literacy and Deaf Culture

The National Library of Medicine defines health literacy as: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Nielsen-Bohlman, Panzer and Kindig 2004, 4). Characteristics of the individual as well as his or her culture, society, and immediate community influence the capacity for health literacy. Proficiency in reading, writing, and numeracy are among the skills enabling greater health literacy; as important, according to many educators, are listening and speaking as well as the broader cultural framework which invest data with meaning and link new information with conceptual knowledge. As one review of the literature on health literacy has concluded, “current assessment tools and research findings cannot differentiate among (a) reading ability, (b) lack of background knowledge..., (c) lack of familiarity with language..., or (d) cultural differences in approaches to health and healthcare” (Nielsen-Bohlman, Panzer and Kindig 2004, 6). The studies of health literacy reviewed, which focus on the hearing population of the United States, show that the obstacles and consequent limitations in basic knowledge most often confront older adults and individuals of any age with limited education or limited English language proficiency. The vast majority of seniors in our sample relied on ASL or another signed language for communication; almost three quarters of the sample said it was “very important” for them to receive healthcare information in their language (see Figure 4). Our study corroborates other research on the limited English reading proficiency of many Deaf adults, suggesting that what may be said of barriers impeding the dissemination of healthcare information among non-English *speakers* and readers, will be compounded by deafness.

Deaf people have different preferences for communication.
What is your preference? ASL, Signed Exact English, Lipreading, Finger-spelling, Voice, something else?

DEAF PEOPLE HAVE PREFERENCES COMMUNICATION, DIFFERENT, DIFFERENT, DIFFERENT. YOUR PREFERENCE, WHAT?

	N	% Responding
6. ASL	97	77.6
7. Signed English	10	8.0
8. Lip Reading	3	2.4
9. Finger-spelling	3	2.4
10. Voice	0	0.0
11. Other/combination	12	8.9
Total	125	100.0

How important is it for you to get health information in the language you prefer?
YOU PICK_____ (repeat response) NOW TELL-ME (TO) GET HEALTH INFORMATION, HOW IMPORTANT USE? HOW?

	N	% Responding
1. Very Important	89	71.2
2. Important	28	22.4
3. Somewhat Important	6	4.8
4. Not very important	2	1.6
5. Not at all Important	0	0.0
Total	125	100.0

Figure 4: Language Preference

Although a causal relationship between health literacy and health remains to be established, studies finding an associations between limited health literacy to poor health appear to be increasing (Nielsen-Bohlman, Panzer and Kindig 2004, 81). The consequences of limited health literacy, while difficult to establish, embrace ethical as well as economic dimensions of health policy (Allen et al 2002; Nielsen-Bohlman, Panzer and Kindig 2004; Giloth et al 2004). Econometric measures predict higher inpatient spending and emergency care costs for individuals with limited health literacy, controlling for health status (Nielsen-Bohlman, Panzer and Kindig 2004).

Health literacy, like literacy broadly conceived, is often context specific, and must, furthermore, be understood as the result of a continuous evolution of experience and social learning. The activities of the Project team in the Deaf community suggested that linguistically and culturally appropriate research instruments were the first step in designing educational materials to improve access to knowledge about end-of-life care concerns and decisions for Deaf adults and their families.

Signed Language and Community-Based Participatory Research

In addition to technical and ethical concerns about language and facility with English, we were also aware of cultural differences that influence our findings as well as the care and education of the Deaf elderly. Language and culture are necessarily connected, as anthropologists have shown (Agar 1994, 60). The “Deaf experience” of our sample population was profoundly influenced by the residential school experience and subsequent outcomes that is central to aspects of Deaf culture.

One such outcome of the residential school was noted in anthropologist Gaylene Becker’s 1976 pioneering study of Deaf seniors. Becker found that her respondents developed a peer learning process as “a formalized mechanism for coping with the information vacuum” (Becker 1980, 66-67). Peer learning is unlikely to address the individual’s lack of family medical history, however, and it may not be a reliable source of public information, including news about health issues. As Becker also notes, information reliability is desirable, but difficult to maintain. As she explains, when stories are incomplete, people speculate; in any community, when the data do not add up, people bring as much coherence to the matter as they can, but rumor and misinterpretation often abound. On-going access to information is crucial to correcting misperceptions and, more importantly, preventing the amplification of errors in peer learning networks. Such earlier research findings played an important role in our efforts to assess the needs of the Deaf elderly for end-of-life care information.

To summarize this overview of research as it relates to our study, we conclude that self-administered English language questionnaires will be less effective in collecting reliable data than interviews conducted by Deaf interviewers in ASL. Furthermore, available research suggests that translations of English language questionnaires by non-native ASL users are likely to be ineffective in capturing the subtleties of cultural differences between members of the Deaf community and hearing ASL interpreters. Finally, existing research on suggests that members of the Deaf community must be an integral part of all phases of research if we hope to collect and interpret data reliably.

THE STUDY

Overview

On September 12–14, 2001, 130 Deaf senior citizens attending the Deaf Seniors of America (DSA) conference participated in 30-minute interviews about their experiences and issues related to end-of-life care. The probability sample was drawn from the DSA list of 1000 registered conference participants. Invitations that included a form for scheduling an interview during the conference were mailed to the participants. Potential participants were contacted by fax, TTY, or email (according to their preference) to remind them of their appointments. These invitations, which were added to the general DSA conference mailing, confused some conference attendees, generating multiple contacts with the randomly selected group and their peers. News of the study spread quickly throughout the national networks of the Deaf community and we soon had a significant number of “volunteers” who contacted us, hoping to be interviewed. Subsequent volunteer recruitment proved vital to the project when

the events of 11 September made it impossible for about half of the probability sample to attend the conference. Individuals participating in the interviews represented 33 states and all regions of the United States. Initial statistical analysis of the data show no significant differences related to our study's objectives between the probability sample and the volunteers. Key demographic information was collected from a self-administered English language questionnaire prior to the interviews. Answers to these questions were validated throughout the depth-interviews conducted in ASL by the fourteen Deaf interviewers, who we had recruited and trained in two, three-hour sessions where they learned research protocol and interviewing techniques. In addition to the majority of respondents who used ASL as their primary means of communication (97 respondents, 80 percent of the sample) about a fifth of the randomly selected respondents indicated their preference to have the study administered another signed language when they returned their study registration cards. The final respondent pool included twenty-eight individuals who requested that their interview be administered in Conceptually Accurate Signed English (CASE), the Rochester method (emphasizing finger spelling), or the Oral method, which incorporates speech and speech reading (Solow 1981). Members of the interview team accommodated these requests as well as the needs of one deaf/blind individual who had been randomly selected for the sample.

Interviews ranged from 30-40 minutes and covered nine topics: 1) English reading and media use; 2) information dissemination; 3) obstacles to receiving information; 4) experiences with healthcare, especially communicating with a doctor; 5) end-of-life care and hospice; 6) decision making; 7) death and Deaf culture; 8) the Deaf community and 9) Deaf self-identification. Interviewers coded responses to closed-ended questions during the interviews. The one hundred twenty-eight interviews were recorded digitally and on VHS (two respondents declined to be videotaped) in five enclosed interview areas set up in a meeting room at the conference hotel. A video monitor, placed in the center of the room received direct feeds from each of the cameras that recorded activity in the interview booths. This technology allowed us to switch among booths to monitor interviews and identify and address problems.



Figure 5: Interviewer Set-up

A long mirror placed next to the respondent allowed the camera to capture both the interviewer signing questions and the respondent signing an answer (Figure 5). This set-up enabled us to capture questions and answers as a check on consistency, interviewers' use of discretionary probing questions, and problems or concerns with question wording in order to confirm interviewer reliability. Recording the responses of Deaf seniors also reflected our method for accommodating the requirements of a visual language, enabling members of the Deaf community to participate fully in subsequent aspects of data analysis. Interviewers also coded responses to the questions during the interviews providing data for preliminary analysis. A complete review of the data required a detailed content analysis of the videotaped interviews, based on content categories generated in focus group discussions held with members of the Deaf community who are uniquely qualified to interpret the respondents' narrative explanation of their answers to our questionnaire.

Using CBPR to Develop the Questionnaire

From their experience with patients like Carl and Clara, mentioned earlier, The Minnesota Deaf End-of-Life Care Project team learned that they needed more information about the population they serve: How could the Deaf elderly best gain access to end-of-life care educational materials? What did the Deaf elderly know about this topic? What did they believe they needed to know? The Project team engaged two hearing social scientists to discuss the principles of CBPR and collaborate with members of the Deaf community to design a questionnaire and undertake the study.

Using standard survey research techniques, the principal investigators designed an English language interview schedule using validated measures of constructs when such questions were available. Leaders in the Deaf community (selected because of their years of experience in the Deaf community, participation in Deaf organizations, or their occupational expertise) discussed and revised the interview schedule in individual consultations and focus group settings. These sessions helped identify oppressive or intimidating questions, confusing question wording, and questions that reflected "English" cultural assumptions that were inappropriate to the Deaf cultural experience.

Some changes were surprising; for example, standard media use items failed to give reliable responses and even the apparently straightforward question: *How much do you understand when you read the newspaper?* overestimated reading comprehension. One of our Deaf consultants explained that we must first ask which sections of the newspaper the respondent had read (headlines, sports, news stories, etc.), otherwise we might measure only that the respondent understood some proportion of the comics or the headlines. After more than a dozen iterations of critique and revision, two pre-lingually Deaf University professors were trained in interviewing techniques and the survey tool was pre-tested on a small sample of Deaf seniors.

Following further revision of the instrument, one of the interviewers was selected to sign the questions and create a practice videotape. At this stage of the instrument design phase, the researchers became aware of the wide latitude interviewers might have in interpreting, translating, and signing the English questions. Concerns with interviewer reliability (signing the questions consistently) were first addressed by use of the model videotape. A lead Deaf interviewer met with the other thirteen interviewers to describe how to use the model tape as a

guide in preparing for administering the interview schedule. The interviewers included linguists, teachers of ASL at the elementary, secondary and post-secondary level, Deaf ministers, and other professionals for whom ASL was their native language.

During the interviewer training sessions, these individuals also functioned as a focus group to determine question wording after the research team explained the intent and objective of each question. In these discussions it became clear that the linguistics of ASL would have a tremendous impact on all levels of our research. Even with agreement on question wording, disagreements about the specific signs that best represented the intended meaning of the question and the inflection to be used in distinguishing the intervals enumerated on the Likert scales remained. Scientifically reliable responses required the interviewers to reproduce the scalar intervals consistently; the content validity of the intervals, thus depended entirely on the consistent presentation of the non-manual adverbial markers of ASL. Despite initial skepticism about the reliability of these “facials,” the investigators observed and accepted that their place in the linguistic structure of the language are no different than English grammar rules that govern the use of adverbs and adjectives. Decisions about the use of particular signs were made by the now-expert interviewers through consensus (a cultural preference for decision-making). Nevertheless, the significant differences between spoken and written languages and a visual, manual, and spatial language raised doubts about the effectiveness of the training video in ensuring reliability. The lessons we learned in translating our English-language questionnaire into ASL hold broader implications for communication in signed languages in research—and in healthcare settings.

GLOSS—Successful Interview Training and Reliable Data

Although we believed we had faithfully recorded in English the back-translation of our experts’ final decisions in ASL, in truth, we had failed. The interviewers worried that the translations represented on the training video were open to alternative interpretations and, indeed, they generally failed to render the English into a consistent set of signs. Our next step, also unsuccessful, was to engage the assistance of a bi-lingual (but culturally Deaf) senior citizen to write simple English sentences in ASL word order omitting the parts of speech that do not exist in ASL. Although we were moving in the right direction, our interviewer team found our representation of the ultimately unintelligible, if perhaps amusing. Our interviewer focus groups reminded us that there is no written form of ASL, suggesting that we use ASL-GLOSS to represent ASL equivalents of English. The representation of English in GLOSS required advanced linguistics skills available to only a few of our Deaf consultants or interviewers. ASL was not recognized as a legitimate language until the late 1960’s, making it unlikely that many deaf people would have learned such a skill or, in many cases, even the rudiments of ASL grammar and syntax. One of our younger, more recently educated interviewers had the GLOSS skills we needed. Ultimately, GLOSS, the unique ASL linguistic method for translating and transcribing the cognitive equivalent of an English word or phrase, allowed for the reconstruction of the interview schedule in a uniquely “Deaf” final form.⁵

⁵ GLOSS represents the common English equivalent of an ASL signifier, or sign. For example, in the English question, “Should ASL interpreters be available for on-call emergency use?” the concept “on-call” was rendered in GLOSS as GO-GO-GO, meaning essentially, always ready to go or continually ready.

GLOSS is defined as English word or words used to represent a particular ASL sign in its most common meaning. GLOSS is not a written form of ASL, rather it represents common English equivalents of ASL signifiers (Valli and Lucas 2002). Although post-secondary schools, (e.g. Gallaudet University) teach this linguistic method and GLOSS has recently been introduced in primary grades as an aid to English language writing instruction (Mozzer-Mather 1990), “translating” from English to GLOSS is an advanced skill. Our team was fortunate to have a Deaf member with this advanced skill. Deaf interviewers with advanced degrees in ASL and linguistics understood the role that GLOSS could play in addressing the challenges that the investigators faced. Though most Deaf people do not have the linguistic skills to change English to GLOSS they had no difficulty reading GLOSS and signing it as written. GLOSS, in its complete form, represents all aspects of ASL (facial expressions, indexing or referring to a person or object spatially and body or role shifting.) Different use of any of these ASL grammatical markers can completely change the meaning and intent of a sentence. A signer, using the exact signs for TODAY RAIN, PICNIC CANCEL can change the meaning of this sentence by adding the co-occurring facial, “eyebrows up.” With no facial, the sentence reads, “It’s raining today, and the picnic is cancelled.” With eyebrows up, the meaning changes to “If it is raining today, the picnic is cancelled.” (Corina, Bellugi, Reilly 1999.) The Deaf interviewers however, felt that because of their intense participation in interpreting the meaning and intent of the questions, reading GLOSSED sentences written in BOLD uppercase English would be sufficient—it was not necessary to grammatically diagram co-occurring facial expression and manual signs. The GLOSS method proved to be the methodological discovery—a breakthrough resulting from the collaborative research approach—that addressed the threats to the study’s reliability and validity by ensuring that the questions would be asked consistently in every interview.

Adaptation of Likert Scales

Likert scales are traditionally used to assess degrees of agreement or importance, as in “Do you strongly agree, agree, disagree, or disagree strongly” with this [given] statement. As we observed in our discussion of pain analogue instruments, scalar representations ranging from left to right may not work effectively with ASL users, who more typically arrange degrees of measurement vertically and, in general, convey myriad meanings through a complex array of spatial orderings. Following the advice of a Deaf psychologist with whom we consulted, we changed the traditional horizontal scale to a vertical scale to accommodate ASL spatial reference points and non-linear attribute of ASL. Simply put, our consultant said, “everyone knows ‘up’ and everyone knows ‘down.’” ASL also has its own numbering system. This does not mean that English numbers are not understood, it does however require that potentially serious ill Deaf patients “translate” a scale with numerals 1 – 5 below a line and facials above a line into a meaningful way to communicate their level of pain.

We encountered other problems in the conceptual response set for Likert scales, including the function of negation in ASL, especially the prohibited use of double negatives. Much like the English use of a rhetorical question—“You wouldn’t want some ice cream, would you?”—as an affirmation, narrative conventions in ASL include the rhetorical use of negation to signal a speaker’s desire for confirmation or agreement: an insidious source of bias to the unwary researcher. In ASL, double negation results in a nonsensical loop of

“cancelled” meanings, compounding the problem of interpretation. For our research, ASL convention required us to recast scale categories so that, for example, “Not very important” became *IMPORTANT LITTLE* and “Somewhat important” became *SO-SO*. After reading the ASL question, the interviewer prompted respondents using 8 ½” x 11” cards showing numbered scalar categories, a device suggested by one of the interviewers that greatly facilitated the speed and ease of interviewing. The scalar categories appeared in GLOSS on one side of the card and English on the other side, giving the interviewer flexibility in accommodating literacy skills of Deaf interviewees.

Questionnaire Layout

Our twenty-two page survey went through fourteen complete revisions, including changes to the layout that improved the visual accessibility of the instrument. Interviewers had 30 minutes in which to ask 64 questions and code responses. To facilitate the administration of the questionnaire by people who rely solely on visual cues, we formatted the entire survey in two columns and color-coded sections. (See Figure 6).

Topic # 3 – Questions about Obstacles in Getting Information	
I will ask you questions about obstacles/frustrations in getting health information	
⇒ Deaf people have different preferences for communication. What is your preference? 12. DEAF PEOPLE HAVE PREFERENCE COMMUNICATION, DIFFERENT, DIFFERENT, DIFFERENT. YOUR PREFERENCE, WHAT? <i>(sign list in right column ⇒)</i>	ASL Signed English Lip reading Fingerspelling Other
⇒ How important is it for you to get health information in the way you prefer? 12. YOU PICK _____ <i>(repeat response above)</i> NOW YOU-TELL-TO-ME UNDERSTAND HEALTH INFORMATION, HOW IMPORTANT USE? HOW IMPORTANT? <i>(sign list in right column ⇒)</i>	1. Very important 2. Important 3. Somewhat important 4. Not very important 5. Not at all important 1. VERY IMPORTANT 2. IMPORTANT 3. IMPORTANT SO-SO 4. IMPORTANT LITTLE 5. NOT IMPORTANT

Figure 6: Questionnaire Format

The topics of each of the nine section of the questionnaire were represented in green. The English version of the question (black) was followed by the GLOSSED version in bold uppercase. Short instructions to guide the interviewers were in red while the scalar representations appearing in the second column were in blue. The Likert scales appeared in written English followed by a GLOSSED version of the scale. The interviewer focus groups and instrument pretests confirmed the importance of the visually oriented, color-coded layout

of the questionnaire presented in English and ASL GLOSS. Ultimately, every aspect of the survey instrument was designed to accommodate the demands of a visual, manual language. From the color coding and page layout, to adaptations of the Likert scales and the use of ASL-GLOSS, our questionnaire reflected the collaboration of hearing researchers and members of this distinct linguistic minority.

CONCLUSION

This chapter highlights a cross-cultural research strategy for research in the Deaf community, suggesting how full participation of Deaf citizens as experts in their culture enable a research process designed to overcome cultural barriers to research, and potentially health knowledge. Using CPBR, we were able to engage the Deaf community's expertise to design a questionnaire and interview format that has allowed us to collect reliable valid information about Deaf seniors' end-of-life care knowledge, attitudes, preferences, desires, and experiences. Our study confirms that language and cultural differences matter, whether researchers are gathering data or care providers are disseminating healthcare information. Ninety-two percent of our respondents told us that they learn best when information is presented in a visual format and that complex information is most easily understood in a signed language; about ninety-four percent indicated that it was important that they receive health-related information in their preferred language. Deaf individuals who cannot access general information in their language cannot fully participate in meaningful conversations in the public arena. Lack of access to health-related information raises issues of ethics and economics in healthcare policy and practice.

Our experience with CBPR confirms that the participation of members of the Deaf community enabled us to identify ethical dilemmas posed by linguistic and cultural differences as well as the impact the lack of background knowledge has on an individual's health literacy. The ethical issues implied by our results continue to emerge as we work with members of the Deaf community in focus groups designed to help us interpret our data. Thus far, it seems clear that visual media, ASL is the best way to convey healthcare information to the Deaf community. Our research experience suggests that Deaf people must be a part of the team charged with designing and presenting such instructional media. In this case, doing *with* rather than doing *for* a community is much more than a slogan. Collaboration may be the only approach that can bring members of the Deaf community the information they need to make informed, thoughtful decisions about their care; collaboration in developing intervention activities and strategies for practitioners who provide services for this unique languaculture may, likewise, be imperative. Finally, we note that "culture" and social learning are both ongoing activities in all human communities. Communities and individuals are shaped by their experiences. The activities involved in community based *participatory* research uniquely respond to the shared learning across cultures that enhance health literacy, resulting, in the present study in widely disseminated educational materials about end-of-life care decisions.

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